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ABSTRACT

This guide is designed to help families identify and explore common questions, concerns, and dilemmas as they consider the advantages and drawbacks of raising a child with severe physical disabilities at home or arranging for care in a residential program. Chapters address: (1) options for the care of children with severe physical disabilities in the past and the present; (2) choosing home care; (3) considerations in choosing residential care including the physical burden of care, the child's age, the parents' ages, the make-up of the family, social isolation, the type of disability, the lack of community services, the need for specialized training, and the financial stress of providing care; (4) the emotional effect of looking for residential care, preparing the child for residential care, and dealing with siblings; (5) benefits and disadvantages of residential care for families and children; (6) choosing a residential program and considering location, staffing, social environment, involvement of parents, and educational programs. A list of family resources on disabilities is provided. (CR)

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Choosing Home or Residential Care

A guide for families of children with severe physical disabilities

ED 428 495

Pedro "Page" Heredia

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Choosing Home or Residential Care

A guide for families of children with severe physical disabilities

By Marilyn Lash, M.S.W., and Paul Kahn, M.Ed.

Marilyn believes that parents are the ultimate experts on the care and needs of their child, particularly when a child has a disability. She has written many guides for families and developed training programs for professionals that are based on the direct experiences and recommendations of families. As Director of Lash & Associates and Assistant Clinical Professor in the Department of Physical Medicine and Rehabilitation at Tufts University School of Medicine, she has drawn upon her clinical training as a social worker and experience as an educator and researcher to present sensitive and practical information to help families and the professionals who interact with them.

Paul is a psychotherapist and writer whose personal experience of living with a progressive physical disability has heightened his awareness of the challenges that individuals and families face. He is the Consumer Coordinator at the Research and Training Center in Rehabilitation and Childhood Trauma at New England Medical Center and is on the staff of the Dept. of Psychiatry at Beth Israel-Deaconess Medical Center in Boston. He believes that persons with disabilities and their families can enjoy a high quality of life if they are provided with adequate physical, psychological, and educational support and if architectural and attitudinal barriers to their participation in society are removed.

Acknowledgments

The drawings in this book were produced by the students at Crotched Mountain Rehabilitation Center.

The Mission of the

CROTCHED MOUNTAIN FOUNDATION

is to assist children and adults with disabilities achieve optimal growth and independence

Founded in 1936 by Harry Alan Gregg, the Crotched Mountain Foundation is committed to the goal that each client can make measurable gains toward an enhanced level of independence in the community of his or her choice.

The Crotched Mountain School and Rehabilitation Center in Greenfield, NH, is a fully accredited school and a licensed specialty hospital which serves more than one hundred students with disabilities in grades K through 12. In addition, the center provides rehabilitation services for young adults who have an acquired brain injury.

Through program offices located throughout New England, the Crotched Mountain Foundation supports many community-based programs including apartment complexes, care management, and care coordination services for the elderly and for adults with disabilities.

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In Appreciation

Too often, families with children who have severe physical disabilities do not have the opportunity to meet or talk with others in similar situations and to benefit from what others have learned. This guide is an opportunity to do so. It is based on the experiences of many families who have raised and cared for their children at home, as well as families who have moved their children to a residential program. Many professionals, who have talked with families about their options and helped them carry out their decisions, also have shared their knowledge and expertise.

Chester Bowles recognized the need for this information and was instrumental in securing the support of the Crotched Mountain Foundation to develop this guide. His guidance with every stage of this project has been most helpful and is greatly appreciated by the authors.

Special thanks are due to the following parents who so willingly shared their thoughts and emotions, including their hopes and sorrows: Cathy Carlton; Mat, Mat, Jr., and Laura Eddy; Doug and Cathy Goodwin; Clare Gorman; Robert and Betsy Hersam; Rudy King; Neil and Marion MacDonald; Sheila Miller; Eldon and Janet Munson; Betty Peiper; Peter Tomaszczuk and Peter, Jr; and William and Cindy Yuknewicz.

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Why This Guide Was Written

A mother of a child who survived a near drowning talks about the stresses of home care.

"Alan needs care 24 hours a day. We have nurses coming into the home, but you never know when they'll call and cancel a shift. If we have no night nurse, I'm up all night and exhausted the next day. Friends and family think I'm crazy to devote my whole life to my son. They avoid us. To tell you the truth, I don't feel I have much in common with them since the accident. We've lost so much. We've learned to take pleasure in little things, like a smile that shows he knows us, or a flicker of interest in a TV show. That's what keeps us going."

When asked how she sees the future, an expression of dread comes over this mother's face.

"I don't know what I'd do if I were ill or dying and couldn't take care of Alan," she admits. "The idea of putting him in some cold, uncaring institution horrifies me. I know I should be making plans, but thinking about these things is too overwhelming."

In another home, a father and his teenage son who has muscular dystrophy discuss the son's plan to move to a residential school. Ted says,

"I met some kids at summer camp who live there. It sounded neat. They have wheelchairs, basketball, hockey, and a pool with a lift in it. I could do so much. I could have friends like me and not get stared at for being different. Around here, all I do is come home from school and watch TV. I'm sick of that."

Asked how he would feel about his son moving away, his father says,

"I know he needs to become independent. I know the local school can't give him the special job training he'll need to work and have a good life. But," he adds, his voice low and his head bowing slightly, "There'll be a void. I'll miss him." "Come on, Dad. You promised—no tears," the son chides gently.

A third parent sits in the social worker's office at a pediatric nursing home, where her daughter, who has been severely disabled

from birth, has been a resident for four years.

"I went through months and months of agonizing before I decided to put Julia here," she remembers. ***"But, after taking care of her for three and a half years, I realized I couldn't do it any more. She needed 24-hour nursing care, but I couldn't get nearly that amount of home nursing hours. She was getting older and heavier. I had other children that I was neglecting. I think I was headed for a nervous breakdown, trying to do everything."***

Asked how she feels now about her decision to place her child, this mother sighs and says with a mixture of sadness and resignation.

"I still feel guilty, like this isn't the way it's supposed to be. If Julia could talk, I'm sure she'd tell me she'd rather be home. I still worry that no one will give her the care I could or that she might be mistreated. But I don't worry as much as I used to. I've gotten to have more trust in the staff here. And at least we're sane now at home."

This guide was written for these families and many others like them. Its purpose is to help families identify and explore common questions, concerns, and dilemmas as they consider the advantages and drawbacks of raising a child with severe physical disabilities at home or arranging for care in a residential program. Many families go through tremendous emotional pain and uncertainty as they ask themselves whether they can provide for their child's needs at home, how long they can continue to do so, what is ***"best"*** for their child, what is ***"fair"*** for others in the family, and how to plan for the future. Many families feel very alone as they struggle with these questions.

There are no easy answers nor any right or wrong choices. Each family needs to decide what is best at any given time, based on their particular situation. The decision to seek or not seek residential care is not typically a one-time event or a short-term process. Just as the needs of the child who is disabled change, so do the needs, abilities, and resources of the family.

Many families who read this guide will already have cared for a child who is very disabled at home. Others, with a child who

is hospitalized because of illness or injury, may be just beginning to determine whether home care is possible for them.

In the ideal world, each family would be able to raise a child with severe disabilities at home and would receive all necessary physical care, medical, therapeutic, educational and recreational services, financial resources, and emotional support. Unfortunately, the reality described by experienced families is quite different. Services in the community are often inconsistent and inadequate. Limits on insurance coverage and public funding strain family budgets. Isolation, rather than support, is the experience of many families with a child who is very disabled.

Rarely do parents find an ideal fit between what is available and what they would like to have for their child. Parents of a child with severe physical disabilities must be constantly reevaluating what their child and others in the family need as they try to find a balance in their lives—now and for the future.

This guide offers a starting point to help parents reflect on critical questions about:

The past: How have the needs of your child changed and how have they affected your family over time?

The present: What are the greatest benefits and stresses in how you are currently meeting your child's special needs?

The future: How can your child and family prepare for the future?

By thinking through these questions and gaining from the experiences of others, families will become better able to make one of the most difficult decisions of their lives—the choice between home care and residential care.

Chapter 1

Options for the Care of Children with Severe Physical Disabilities: Past and Present

The rewards and stresses of raising a child who has severe physical disabilities are different for each family. The special love of a parent for a child is what makes it possible to meet and overcome the many struggles, challenges, and disappointments over the years. Parents talk about the importance of holding on to hope that their child's condition will improve. Progress takes on a new meaning for these parents. While major improvements are readily noted by professionals, parents more often see small changes that make a difference in the quality of their child's life. Less visible to others, these improvements are important to their child and family.

For most families with able-bodied children, the responsibilities for physical care are most intense while children are very young. The burden of physical care eases as children develop and become more self-reliant and independent. As they enter adolescence, they begin to develop the social, academic, and vocational skills that will prepare them to become independent adults. Families expect that their children will grow up, leave home, work, marry, and raise families. Often, as parents age, they look to their children for emotional support and even physical help.

When a child is severely physically disabled, however, life is different for the entire family. Rather than a lessening of parental responsibility and care, a child's development raises additional concerns about the future and how the child's needs will be met.

What Is Meant by Severe Physical Disabilities

Disabilities can be caused by genetic disorders, birth-related conditions, chronic illnesses or traumatic injuries. Some children have medical conditions that are stable. Others have conditions that cause progressive loss of abilities. The kind of disability affects the family's expectations for their child's development, achievement, and life expectancy.

A child who is severely physically disabled may need help with eating, bathing, dressing, and toileting. A child who has difficulty breathing may use oxygen or a ventilator and even require regular suctioning to clear the lungs. Swallowing disorders or nutritional conditions can result in special diets and tube feedings. A child's paralysis, muscle weakness, or poor balance may require wheelchairs, special equipment, and architectural changes at home. Communication can be difficult and frustrating when a child's speech or hearing is affected. Poor vision adds the worry of safety and difficulty with social interaction. Many children have seizures that require special precautions and medications.

But these children need more than physical care. They also have cognitive needs to learn and communicate, which require special educational services. Some children are mentally retarded as well as physically disabled. Others have difficulty learning. Some have emotional or behavioral problems. Some disabilities do not affect a child's intelligence, but the child may need help with the physical tasks involved in learning, such as writing or turning the pages of a book.

A Historical Perspective

Years ago, parents were commonly advised by physicians and other professionals that a child who was severely physically disabled would be ***"better off"*** in an institution or state school with trained caregivers. Parents who chose to care for their child at home often did so with little support from professionals and needed courage to defy the conventional ***"wisdom"*** of the time. Children often were described as ***"brain damaged, vegetables, and***

imbeciles." Parents were frightened by grim predictions for the future and given little hope for their child's development. Institutions were set up for basic physical care, and too often the quality of the child's life suffered.

Most medical and social service professionals believed that a child with severe disabilities should not be raised at home for several reasons. First, they thought that care at home was too much of an emotional strain on the family. Second, parents were seen as incapable of giving complex physical help and nursing care. Third, raising a severely disabled child at home was believed to affect siblings negatively. There was less concern about removing the child from the family, since little was understood about the emotional and social needs of a child with severe disabilities.

Before the first federal law for special education was passed in 1975, children with severe physical disabilities did not have the right to a public education and often were not allowed to attend local schools. Many parents reluctantly sent their school-age children to a state school or facility because that was the only way they could get an education. Others kept their child at home and patched education together through home tutors and parental instruction. Educational services were so limited that often they could be counted in the number of hours rather than days per week.

The Shift in Attitude

Society's attitudes about persons with disabilities have changed slowly over the years. No longer is it assumed that a child who is severely physically disabled should be raised in an institution. In fact, the pendulum has swung the other way, and tremendous value is placed on keeping families together. This has raised doubts and caused guilt in families who consider residential care.

Many state schools and institutions have now closed, and children with severe disabilities are living at home and attending local schools or special day programs. However, many parents have found that despite the promise of the law, local schools still find it hard to meet the complex needs and challenges of educating a child with very severe disabilities.

Current Options for Residential Care

Residential care means that a child lives and is cared for in a program outside the home. This does not mean that a child who enters a residential program will never return home, or that the child is no longer part of the family. Children enter residential programs at all ages for different lengths of time. Some have short stays to reach specific goals and then return home. Others stay longer and eventually move on to special programs or residences for adults. Some children enter residential care after a hospital stay; others are admitted from home.

Payment for residential care varies among states and programs. Most parents of a child with severe physical disabilities quickly become informed about the limitations of health insurance coverage and rehabilitation and home care services. Parents have to learn about additional funding mechanisms, including public programs. Funding is complicated even more by the special educational needs of a child who is severely physically disabled. Age also can be a factor. Funding for residential services is often a complicated mix of resources that includes special education as well as public and/or private programs.

There are many different types of residential care. Not all are available within a family's local area or even within each state. Therefore, parents sometimes face tough choices when looking for a program that can meet their child's special needs.

The following are descriptions of common types of residential programs for children with severe physical disabilities.

Residential Program Choices

Pediatric Nursing Home

It provides nursing, therapeutic, and medical services to children with complex medical conditions requiring skilled nursing care. A pediatric nursing home may have a school program, which may be only for its residents or include day students.

Foster Care

Most parents think that foster care is only for children who have been physically or emotionally abused and removed from their home for protection. However, there also are foster families who provide special care in their homes to children with complex medical needs.

Group Home

Many communities have built or bought private residences where children with special needs live together and have care and supervision provided by 24-hour trained staff. Homes vary in the number and age of residents and the complexity of care that can be given.

Residential School

This program combines a school and residence in one location. Residential schools vary in size as well as in students' ages and grade levels. Children stay all year in some residential schools; in others, they go home for weekends, vacations, and/or summers. Some programs are state supported; others are private.

This is not an exhaustive list. Each type of program has advantages and drawbacks that families must evaluate. Much of the frustration that parents experience as they consider their choices comes from the scarcity of resources and the resulting need to constantly advocate for their child.

Summary

Whether or not a child lives at home or in a residential program, parenting never ends. There are bonds between parents, children, and siblings that extend far beyond where each lives. The responsibilities continue over the lifetime of the child as well as the lifetime of the parents. While much is available for the medical care that enables these children to survive, there is far less to support their quality of life as they grow up. The future is of special concern for many of these families. Where will their child live and what kind of life will their child have?

"Shortly after our son was born, we knew there were problems. After several weeks of tests and consultations, we met with the doctors. I can still remember hearing a long list of at least twenty diagnoses and complications. My initial reaction was that he could not possibly survive. It was when we were told that he had close to a 'normal' life expectancy that I had my first glimmer—and shock—of what the future held for us."

Chapter 2

Choosing Home Care

Many parents fear that the ***"human touch"*** will be lost in a web of efficient medical care given by professional staff in a residential setting. The wish to keep a child at home within the security and love of the family is often the driving force behind the complicated planning and work of home care. But converting the home into a place where specialized care can be given takes a lot of forethought. And it needs to be done while remembering that the house is still ***"home"*** to everyone who lives there. Finding the balance for everyone can be very tricky and takes a lot of trial and error.

In order to make home care manageable when a child has a severe physical disability, parents need specific knowledge and skills. Without these "tools," no one can possibly do this job without incredible stress. In fact, experienced parents admit that home care may never be easy, but it can be manageable and bring benefits that are worth the hard work. This chapter gives a quick overview of the needs and priorities of families who choose home care and is designed to help parents evaluate their readiness to begin or continue with it.

Understanding the Home Care Needs of Your Child and the Effects on Your Family

The most basic parts of home care involve the following:

- √ Physical setup of your home and its effect on the safety of your child
- √ Direct or ***"hands-on"*** care of your child
- √ Supplies and equipment needed for your child's care
- √ Emergency care plans
- √ Outside help from resources and agencies in your community
- √ Paperwork and record keeping

The Home Setup

The following basics are necessary for the safety at home of any child with severe disabilities:

- √ Smoke detectors
- √ Fire extinguishers
- √ Electrical service and outlets adequate to handle equipment
- √ Back-up power service, such as generator or batteries
- √ Telephone
- √ Heat
- √ Running water
- √ Space for equipment and supplies
- √ Accessible entry and exit

The setup of your child's bedroom affects how easily and efficiently care can be given. It also affects how comfortable your child, friends, and family members will be spending time there. Therefore, think about:

- √ What equipment and supplies does your child need?
- √ Where will they be kept?
- √ What safety features such as fire alarms, smoke detectors, and flashlights must be in your child's room and in other handy locations?

"Our daughter has a hospital bed and a lot of equipment in her bedroom, but it certainly doesn't look like a hospital room. The walls are bright pink, and we put a lot of her favorite pictures and posters on the ceiling over her bed as well as on the

walls. She still has her stuffed animals to keep her company. The supplies that I need are in a stand next to her bed, but I keep the major supplies stored in a closed closet in her room. Other than all the special equipment, it looks like any teenager's room. When we remodeled the house, we made sure that she would have space in her bedroom for her brothers and sisters as well as her friends to 'hang out.'"

For families who own their home, changing its physical structure is another option, but this can be costly depending on the extent of the changes. If a child uses a wheelchair, doorways may need to be widened, the bathroom enlarged, bedrooms relocated, or ramps built. For a child who relies on electrical equipment, rewiring and additional outlets may be necessary to bring in more power.

Balancing the needs of the child who is disabled with the needs of other family members must be a constant consideration. If the child who is disabled is given the biggest bedroom because space is needed for equipment and supplies, siblings may feel crowded or displaced. If the room of the child who is disabled needs to be close to the parents' bedroom for safety or convenience, then parents need to find ways to have privacy. If home care workers are present during the evening or throughout the night, parents have to think through the logistics of how and where care will be given without disturbing other family members.

Caring for Your Child

Learning how to give care is a continual process as the child grows and as medical conditions and therapeutic needs change. Parents of most children with severe disabilities have to develop competence and confidence in giving medications, performing cardiopulmonary resuscitations, and recognizing signs of complications and side effects of medications. Depending on their child's condition, they may also have to learn how to do chest therapy, suctioning, ventilator care, or nutritional care. Parents of

children with mobility impairments may have to learn special techniques for lifting and positioning, and they may do stretching and strengthening exercises.

"When the nurses in the hospital first started explaining what I would have to learn to care for my son at home, I thought that I could never do it. Now I have more experience than some of the nurses who come to my home, and I help train them."

Organizing Important Information

Certain information is requested often by the people who come into your home to arrange or provide care. A three-ring notebook, file cabinet, or other storage system helps collect and organize materials.

Important information includes:

Medical condition and daily care

- √ Up-to-date medical summary
- √ Specific nursing orders
- √ Medications including actions and use, dosage, frequency, way of taking, side effects, and storage instructions
- √ Therapy exercises
- √ Nutritional needs
- √ Other special treatment instructions
- √ Outline of the child's typical day

Special equipment

- √ Home equipment and supply list
- √ Instructions on use and maintenance of equipment

School information

- √ Names and phone numbers of contact people at child's school
- √ Special learning needs and help with homework
- √ School schedule
- √ Transportation to and from school

Important contacts

√ When to call the doctor

√ Phone numbers of:

- Doctors
- Nursing and home care agencies
- Equipment companies
- Public service companies
- Fire department
- Ambulance service
- Police department
- Closest relatives in case of an emergency

"I found myself repeating and writing some of the same information over and over as the weeks went on, so I put together a short summary of what my daughter's day is like, what kind of help she needs, and tried to include answers to the questions that workers asked most often. I found that it helped new workers get a sense of what our life is like from day to day. But it also helped me look at how I spend my time and energy and to see where I need help the most."

Emergencies

There are basically two types of emergencies that concern parents giving home care. The first happens when a child's medical condition requires emergency treatment. Because children with disabilities usually have complicated histories, many parents are anxious if their regular physician is not available during an emergency or if they visit an emergency department in a hospital where their child has not been treated before. To help insure proper emergency medical care, have your child's doctor write a letter to accompany the child on any visit to an emergency department. The letter should describe the child's special medical problems, baseline data, current treatments, and the primary doctor's name and phone number, as well as those of any specialists.

The second type of emergency is a crisis that occurs be-

cause of an unusual circumstance or event. Parents caring for children at home with complex medical needs worry about how a loss in electrical power, heat, or telephone service could affect their child's comfort or health. Utility and telephone companies need to be alerted in writing of special health conditions, so the home of the child is placed on a priority list for restoring services. Similarly, local fire departments need to be notified of any child who will need special help being evacuated from the home and the location of that child's bedroom. While a letter from a doctor can emphasize the importance of this, and may be required by some companies, it is important that parents double-check these precautions because they are vital to a child's safety in an emergency.

"I get really nervous whenever we have a thunderstorm, because there is always the danger that the power will go out. Even though we have a back-up generator and the power company knows about my daughter, it's always a reminder to me of how quickly we can get into trouble and of how much I have to rely on others for what we need to take care of her at home."

Communication with Home Care Staff

Most often, the tensions that arise between parents and staff (whether they are nurses, aides, or therapists) stem from confusion or miscommunication about needs and expectations; conflicts about roles and responsibilities; or loss of privacy. The effectiveness of communication between parents and home care staff may be the most important factor in determining whether the working relationship is satisfactory. Parents need to communicate their expectations clearly and firmly. Reasonable expectations of the agency and its staff are to:

- √ Provide competent care to the child
- √ Cover all scheduled shifts
- √ Replace any staff not providing appropriate care
- √ Provide regular supervision to staff
- √ Have a process for resolving any problems between the

family and staff

- √ Respect the parents' authority and judgment in all areas of family life
- √ Respect the privacy and lifestyle of all family members, unless some aspect of behavior puts the child at risk
- √ Discuss with parents when to call the doctor or involve anyone else in the child's care, except in an emergency when parents are not available
- √ Keep up-to-date on new techniques and skills that could promote the well-being of the child

Experienced parents suggest discussing specific responsibilities and agreeing upon them in writing before staff begin working in the home. Having detailed instructions in place can lessen or eliminate misunderstandings. Distinguishing between parent and nursing responsibilities also helps both partners understand their roles. The dividing lines often are not firm. For instance, if a child needs help eating, this could be either a parent or nursing task. Families need to think through their preferences about the type of help that is needed, discuss their decisions with nurses, and reach an agreement.

Keeping relationships with home care staff on a professional basis is essential. When parents become too friendly with staff and rely on them for emotional support, they tend to lose the sense of being ***"in charge."*** They are also less able to be objective about performance or to criticize when constructive feedback is due.

Staff employed by agencies are required to keep a written log. Many parents also keep a notebook to exchange information with staff about schedule changes, special appointments, or other new information about their child. In order for the relationship to work, parents have to feel comfortable talking with home care staff. Parents and staff must be able to share their concerns and solve problems together as partners in the child's care.

Summary

Caring for a child who has severe physical disabilities at home is very complicated. The care is not only physical, but also emotional, social, and recreational. It involves a great deal of expense, labor, and love. Whether families do it themselves or with outside help, they must constantly identify and reevaluate their needs and priorities. Home care impacts everyone living in the home, siblings as well as parents. Relationships with people outside the home are also affected. Relatives, friends, peers, and coworkers inevitably have opinions about the benefits and stresses of home care and how the family is handling it.

Often, the focus both inside and outside the family is on how difficult home care can be. But many parents have commented on the benefits of keeping their family together and the importance of raising their child at home. Many also believe that siblings develop a special sensitivity to the needs of others, and an awareness of the fragility of life. They learn to judge less by physical appearances and skills than by the qualities inside a person.

Judging whether or not home care is the right choice for your family can be very difficult. Conflicted feelings arise, as the next chapter details. To get an objective ***"handle,"*** think about whether you have the ***"tools"*** described in this chapter. And periodically step back and ask yourself the following questions:

- √ How do the current home care needs of your child differ from those in the past?
- √ What new skills are required to continue with care at home?
- √ Are additional resources needed to help with care at home?
- √ Are any changes that you see temporary, or are they early indicators of future needs?
- √ Are the pressures and demands of home care increasing with time or lessening?
- √ Do you have enough time to sleep, spend time with other children, work, manage the household, and attend to regular chores?

CHAPTER 3

Why Families Consider Residential Care

Parents want to raise their children at home and struggle to keep their families together. Most often, parents seek residential care only when care at home is too difficult or no longer in the best interests of the child or family.

Physical Burden of Care

The most frequently cited factor that leads families to consider residential care is the physical burden of care. Children with complex medical conditions can require lots of physical care that is strenuous and fatiguing for parents. When children need around-the-clock supervision and monitoring, it's hard for parents to get a solid night of rest. And the demands of care become intensified when children are recovering from surgery or even experiencing common childhood illnesses. For instance, the parents of a nonverbal child with cerebral palsy still recall when their son had an ear infection and cried and screamed all night, trying to communicate his pain. His parents were up constantly, seeking to comfort him and lessen his distress.

The Child's Age

The age of the child is another important factor. As children get older, they get bigger, heavier, and more difficult for parents to bathe, dress, toilet, and transfer. Society seems to

support and accept younger children with disabilities more readily than older children. The qualities that make youngsters ***"cute"*** and appealing help friends and strangers focus on the child rather than the disability. But as children with disabilities get older, society becomes less tolerant of behaviors that seem infantile or childish.

"My daughter is 10 now. I can't change her diapers in front of people any more, like I could when she was a baby."

"People stare at us when my son bangs on the table in a restaurant, or turn their heads when he talks too loud or hollers when he gets upset. I can see them thinking, 'What's wrong with him anyway? Look at how big he is.'"

The Parent Ages

Parents also think about residential care because they are getting older and may be having health problems of their own, just at the time that their children are getting bigger and more difficult to handle. While other parents their age enjoy a lightening of responsibilities as their able-bodied children grow up and become more independent, the parents of children with complex needs find little relief. One mother described her situation as ***"like having a newborn for 20 years."*** On a physical level, parents entering middle age often feel too worn out to continue home care. On an emotional level, they feel deprived of the relief from child-rearing cares that they see their peers enjoying.

"It was never easy caring for Ben, but it's gotten harder as I've gotten older and he's gotten bigger. I just don't have the same strength and energy that I used to. I can't lift him by myself any more."

As aging parents begin to think about their own mortality, they start to worry about how their children will be taken care of when they are gone. Residential placement can offer them some security for their children.

The Make-up of the Family

Rarely is the care and responsibility for a child who is disabled divided and shared equally among family members. Certainly, in one-parent families the stress of home care is apt to be greater. But even two-parent families have a hard time, especially if they are not able to work together to care for their child. For instance, if one parent withdraws emotionally from the child with a disability or does not help out, the other parent can be left feeling isolated and overwhelmed.

"My husband worked incredibly long hours and was almost never home, except to eat or sleep. That was his way of coping with what had happened. I felt totally alone and abandoned, in addition to being physically exhausted almost all of the time. Eventually, I realized that I was really angry at my husband and at the way he was handling this. It wasn't easy for me either, but I couldn't avoid it since I was the one who was home and taking care of our son 24 hours a day."

When there are other young children in the home, parents often feel deeply torn between meeting their needs and those of the child with a disability. The siblings, for their part, can feel jealous and resentful of all the attention and resources that go to the child who is disabled. If peers tease them about the brother or sister who is ***"different,"*** they may withdraw socially or avoid bringing friends home.

When siblings get older, they are often expected to help with care or even become substitute parents to the child with a disability—another potential cause of resentment. When siblings leave home for college or to live independently, parents are faced with coping on their own. This usually occurs just at the time that parents are entering middle age and are less physically and emotionally equal to the demands of home care.

Many parents report that relatives and friends rarely help with home care and, instead, increase the stress upon families by avoiding them. Other families worry that siblings may feel too responsible and too readily assume that they will become the

primary caretaker in the future when parents die or are unable to continue. They worry that the child who says, ***"I'll always be there to take care of my sister,"*** is well-meaning but untested by the realities of the responsibilities, the uncertainties of life, and the need for adult siblings to establish their own independent lifestyles.

Social Isolation

Adolescence brings increased emphasis on appearance and peer pressure to fit in and conform. An adolescent who is different in any way because of a disability can be very lonely. The adolescent who is disabled is often excluded from the usual teenage rites of passage, such as learning to drive, dating, and getting an after-school job. Becoming depressed is all too common. One 17-year-old with muscular dystrophy said he decided he wanted to move to a residential school because he ***"was sick of coming home after school and being alone."*** At this school he felt he would be among peers and ***"not be treated differently."*** Also, he looked forward to enjoying athletics and after-school programs that were adapted to his physical limitations.

Parents also can be isolated socially by the time and energy required to care for their child and keep a household running.

"My husband and I have not been away overnight since this happened. It takes so much of our time and energy to keep our daughter at home that we don't even think about vacations or trips anymore. We don't even go to the movies or have dinner with friends, because everying just becomes so complicated."

The Type of Disability

Clearly, the nature of a child's disability plays a part in the consideration of residential care. Children who need extensive physical care are harder to manage at home, as are those whose care is medically complicated. Children with disruptive behaviors such as aggression put even more stress on families. This is also true of children whose health and comfort change frequently.

One mother said, ***"The whole personality of our home revolved around whether our daughter was having a good day or a bad day."***

When a child has a degenerative condition, parents face the pain of watching their child lose abilities and skills. As the child gets sicker, the demands of care get greater and parents may feel increasingly desperate and helpless. ***"I was driving myself crazy, trying to do everything I could for Phillip,"*** said one mother. ***"I was headed for a nervous breakdown."*** Sometimes parents of children with terminal conditions simply cannot bear to see them die at home and seek residential care for that reason.

Lack of Community Services

Often the struggle of home care becomes too much for families because of the lack of services in the community. Both private insurance companies and public funding are putting more severe restrictions on coverage for home nursing and therapies. Too frequently, even when funding for professional help is approved, it does not meet the needs of the family.

Agencies must adhere to strict policies about what kinds of assistance workers with different qualifications can provide. Registered nurses, licensed practical nurses, home health aides, and homemakers have different skills and training. Their responsibilities are outlined and limited by their job descriptions and the licensing requirements of their employers. For instance, only certain staff can give medications. Others can deal only with specific parts of the child's care. Others can help with household chores but not care for the child. While these restrictions are designed to protect the agency and the child, they can make it harder for a family to obtain the range of services that is needed regularly. Instead of one person caring for the child, families often have many different workers coming into their home throughout the day and week.

"One day I counted up and a total of 18 people had come to the house or called that day about Sara's care. There was the man who came to check the electric controls on her bed, the

person who brings the oxygen, the aide who brings her home from school, the physical therapist for her exercises, the night nurse—there are people calling or coming and going all day long. And then there is the paperwork so that all these people get paid. I couldn't take care of her at home without them, but sometimes it feels like our home is not our own any more."

Many things can go wrong with home care. Sometimes parents feel that the workers supplied by an agency are not qualified to deal with their child's condition. Workers may not get along with the family. Agencies may sometimes cancel shifts with little or no notice. When this happens, parents have to fill in, thereby putting their own jobs in jeopardy, neglecting responsibilities to other family members, or getting little sleep. ***"You can't rely on the agencies,"*** one mother explained. ***"If I could be absolutely guaranteed of nursing coverage, I'd have my son home in a minute."*** Lack of reliable, scheduled respite care to get ***"a break"*** also causes parents to burn out faster.

The Need for Specialized Training

Both adolescents and their parents have considered residential care because of the limitations of mainstream education for students with disabilities. Public schools concentrate on teaching academic subjects within a standard curriculum. Even with the programs and services that can be designed or made available under special education, local schools are likely to have little experience providing the specialized help with independent living skills and vocational training that adolescents with disabilities need to prepare for adulthood. Many families feel pressured to find and take advantage of residential programs that offer expertise in these areas before their children graduate from high school or reach the age at which they lose their entitlement to special education services.

"We were very conscious of the shrinking window of time for our daughter to get the services and training that she needed while she was still eligible for special education. While we hated

to see her leave home, we thought this special program would give her the best chance of getting what she needed in the time she had left for eligibility. We don't really know what will happen next, but we're hoping that the school will be able to prepare her, and us, for whatever it is."

Financial Stress

Still another factor is financial stress. In a two-parent family, usually one parent has to stay home and be the primary care-giver of the child with special needs. This limits family income and puts the burden of financial support on the other parent. In a one-parent family the situation is even more difficult. The single working parent risks being viewed by an employer as unreliable if a medical crisis or a gap in scheduled home care results in taking time off. One divorced father remarked, ***"I could probably disappoint my boss once before I got fired."***

Summary

In summary, parents seek residential care for their children with severe disabilities for two main reasons. First, it may offer the only reliable and available relief from the constant physical, emotional, and financial stresses of home care. And second, it can meet the long-term physical, social, and developmental needs of their children. Whatever the reasons, residential care is usually an option families choose only after a great deal of soul-searching and emotional upheaval.

Chapter 4

The Emotional Impact of Looking for Residential Care

No matter how difficult caring for a severely disabled child at home becomes, a family is apt to feel, **"This is where my child belongs—with us."** Many families have described choosing residential care as the most difficult decision they ever made.

Emotions Shared by Families

Guilt, anxiety, worry, fear, shame, loss, sadness, conflict, and hope are all words that families use to describe their emotions during the decision-making process. Many families struggle with enormous guilt over not having their child at home. Many feel that they have failed their child. No matter how much they tell themselves that residential care is the best option, there is a nagging sense that this is not the way it is supposed to be.

In families where the child is able to participate in the decision-making process and even looks forward to residential care, parents feel less guilt but are still saddened by the separation. The move is seen as the start of a new phase in the family's life cycle. The child will become more independent, and the parents will gain freedom but lose some of their parental functions. Hopes and anxieties always accompany such major life changes.

For parents who have provided care at home since their child's birth, letting go of this responsibility and trusting that others will give good care is very difficult. For those whose child has a shortened life expectancy, there are conflicts about losing some of the precious time that is left to be together as a family.

When a child suddenly becomes disabled by an injury or near drowning, families may be struggling with how life has changed ***"since the accident"*** while also confronting the possibility of residential care.

All families talk about the anxiety and worry they have over the quality of care in a residential program. At home parents have control over their child's care. Giving up this responsibility and control to strangers is enormously difficult. Parents also recognize that, ***"Nobody will ever care for her like I do."*** Parents of children who cannot communicate are especially fearful that staff of a residential facility will not understand their child's needs. They also know that their child will be unable to say if something is wrong.

"One of my biggest fears about residential care is that my son won't be able to tell me if he is mistreated. It's so hard for him to communicate with us, and he will be too far away for me to visit every day."

Many parents worry for a long time about whether they made the right decision. They struggle with conflicts between their intellect and emotions. For a long time, many parents wish that their child was still at home, even when they remind themselves how demanding and exhausting home care had become.

Many parents also feel they are losing their child for a second time when they choose residential care. Having gone through the process of mourning that often follows the birth of a child with a disability, the diagnosis of a chronic illness, or the emotional trauma of having a healthy child become disabled by an injury, these parents have somehow managed to grieve and move on. No matter how good the residential program is, no matter how excellent the care, or how much activity is going on, many parents go through a second period of mourning when the child leaves home. Nurses are never going to be the same as parents. Roommates are not siblings. Therapists are not family.

Sometimes there are tangible reminders of loss such as an empty bedroom, clothing in the closet, ramps at the doorway, and leftover medical supplies. Other changes are not so visible but are

still keenly felt, such as not having to wait for the school bus to arrive. Many parents describe feeling overwhelmed at times by the emptiness at home. Newly available free time can be a painful reminder as well as a welcome relief.

Assumptions about Residential Programs

The emotions that families describe during the decision-making process are reinforced by their limited knowledge. Many parents do not know what to expect when they first visit a residential program. Institutions with bars on windows, unclean rooms and smelly linens, children neglected and left alone in bed or lined up in the hallway—these are just some of the horrors that parents imagine and fear.

"It's important to go and look at programs. Although none were as bad as the images and fears that we had in our minds before we started, some were definitely better and others worse."

Dealing with the System

Many parents experience frustration and anger with ***"the system."*** After the emotional ordeal of making the decision in favor of residential care and looking for a program that can meet their child's medical, nursing, and educational needs, many parents have to undergo a lengthy, bureaucratic process of getting funding approval before their child can be accepted into a program.

Often children with severe disabilities are viewed in terms of what they can *not* do. Many parents talk about their disappointments and sadness over the years as they watch their child's development fall behind that of younger siblings and peers. Repeated consultations often reinforce what their child will not be able to achieve. For many, the struggle to refocus on what their child *can* do involves changing how progress is measured and what is expected.

"I know that the 'normal' milestones and achievements will never be there for my son. I look for smaller gains. And

time has a different meaning for us. No matter how long it takes, it's still progress."

These alternative yardsticks that mark progress and measure time have special meaning for each child and family. But they may be ignored when the child undergoes an administrative and medical review, using strictly objective criteria to determine approval for residential care. Some parents feel that they now have to ***"make the case"*** that it is impossible to continue to provide care at home. This resurrects feelings of inadequacy and guilt.

"We now felt like we had to focus on how disabled our son was in order to get approval for his placement, after all the years when we had tried to focus on what he could do."

While states differ in the administrative requirements for funding residential care, parents everywhere share the emotional stress of going through the application, review, and approval process. It is time-consuming and lengthy. It can be intimidating. It reminds parents that they do not control the vital funding that is needed to get services for their child. It provokes anxiety because so much hinges on the decision. It reinforces how vulnerable their child is to the decisions of agencies, organizations, and payers. And it reminds parents of their child's ultimate vulnerability when they are no longer alive or able to be advocates.

Preparing the Child for Residential Care

Parents are often afraid that their child will feel rejected, unloved, and terrified by new surroundings and caregivers. When a child is too young or cognitively limited to understand explanations or to verbalize feelings, parents tend to feel especially bewildered and helpless. They cannot know if their child understands what is happening or why. They have no way of knowing for sure what their child's feelings and preferences are. Even when a child can understand, there is, as one parent said, ***"no soft way"*** to break the news. Parents feel enormous guilt and grief about disappoint-

ing the child who tearfully pleads to remain at home. Only in situations where the child is in favor of the move do parents feel more at peace with themselves.

After a Child Enters a Residential Program

Many families find that the process of making the decision has been so stressful and drawn out that they are not prepared for the changes in their lives after their child moves to a residential program. While feelings of sadness and loss are common, there are also feelings of relief that the decision has been made, funding has been secured, and the move has been made.

The initial relief for many is physical. Many take a vacation or travel. ***"For the first time in years, I slept through the night."*** But some families feel guilty over feeling relieved from the constant responsibility for care. Many continue to struggle with the decision and ask themselves periodically whether residential care was the right decision and whether this is what their child would have chosen. Some children are very homesick. ***"Telling John that he couldn't come home was the hardest thing I ever had to do."***

A common theme expressed by many severely disabled adolescents living at home is their increasing social isolation as they find themselves without peers and excluded from activities outside of school. For some, summer camps or recreational programs specifically for adolescents with disabilities open up new arenas for making friends, playing sports, and being in an environment where parents are not the constant watchdogs and caregivers. Some adolescents who tire of the loneliness at home look at residential programs as a means of becoming more active socially and more independent and self-reliant outside the protective circle of home and family. This raises some conflicts for parents who are unsure whether their adolescent is emotionally ready to move away from home and has an accurate view of the residential program.

"Even though living away from home was something that our son wanted, we still found it hard to accept and let go.

We had to trust his instinct about what was best for him. He was tired of being the only disabled kid at school, and he had no friends."

When so much time and energy has been put into the care of a severely disabled child, some parents find that they have avoided dealing with their own needs and priorities and put off making critical decisions about their future. Others find that their spousal relationships have been neglected. Being freed from the demands of their child's daily care provides an opportunity to strengthen marital relationships. Others find they can no longer ignore conflicts and difficulties in their marriage. Putting off decisions about marital separation or divorce can no longer be justified by the rationalization that a child's care necessitates both parents living at home. While some rebuild relationships, others separate and eventually divorce.

Siblings

The age of siblings affects their reaction to a child's move to residential care. Young children view the world simply and often confuse cause and effect. Many young siblings believe that they have done something ***"bad"*** that resulted in the disabled child's move. Some become anxious that they might be sent away if they misbehave. Parents find that young siblings need repeated explanations in terms they can understand about why the disabled child no longer lives at home.

Siblings of all ages need ways to stay connected to the child in residential care, whether by cards, drawings, phone calls, or visits. The loss of daily contact is a major change. Siblings may feel relief that, ***"We can finally be a normal family now."*** But they may also have some guilt over feeling this way.

Siblings vary in their reactions to visiting nursing homes, group homes, or residential programs. Some young siblings are frightened by the setting or upset by the presence of so many children with disabilities. Others visit regularly and bring reminders of home, such as photos, favorite toys, and other familiar

objects. Some siblings choose not to visit at all. Parents stress the importance of helping siblings work out what is comfortable for them and acknowledging their feelings without judgment.

Summary

Sorting through the emotions aroused by residential care is a long and often painful process. It has no timetable. Often emotions are stirred up unexpectedly even after families think they have made peace with their decision. Some families find that there are predictable times, such as holidays and birthdays, when they most sharply feel the absence of their child. Each family must find a path through this in its own way.

Chapter 5

Benefits and Drawbacks of Residential Care

Families with children in residential care report many benefits. On the other hand, both families and children experience certain losses and stress.

Benefits to Families

Relief from Care

The most obvious and common benefit is relief from the physical and psychological responsibility of daily care. Parents can get adequate rest and have more energy and freedom to work, spend time with each other, socialize, and go on vacations. ***"We're sane now,"*** one mother with a child in a pediatric nursing home said. A father commented, ***"It's okay to be a little selfish. It's okay to want a life for yourself."***

More Time for Siblings

When parents are no longer exhausted and preoccupied by home care, siblings benefit by getting needed attention. Parents can play with them, go on outings, and attend important events, such as school plays and sports competitions.

"I always felt pulled between caring for our son and my other children. Although they didn't need all the physical help that Sean did, they still needed to be mothered. And I didn't always have the time or the patience to give them. Looking back, they had to grow up too quickly because I couldn't always be

there physically or emotionally. Even though they love their brother, I know they resented how much he controlled our life as a family."

Relationships among siblings often improve without the daily competition for attention that can lead to jealousy and resentment toward the child who is disabled. Residential care may also lessen siblings' concerns or expectations about replacing parents as future caregivers at home.

Security about the Future

Parents may also feel less anxious about the future if a child is assured of continued care in a residential program. They know that, in the event of their illness or deaths, their child will be cared for. This helps parents feel that they ***"have done the right thing."*** This knowledge goes a long way toward diminishing the guilt that parents often experience when they relinquish care.

"My worst fear is that my daughter will end up in a terrible place after I die. I don't want someone else making the decisions about where and how she will live. I feel like this is something I have to do now to protect her future. And if I do it now, I can be there to help her adjust to living in a new place."

The Opportunity to Separate

Parents also say that their relationship to their child who is disabled becomes more ***"normal"*** when they are no longer the primary caregivers. With the coming of adolescence, children and parents need to emotionally and physically separate from each other. This is very difficult if teenagers must still depend on parents for personal care. A teenage boy cannot slam the door of his room and demand to be left alone, if he then has to call his mother to help him use the toilet and get into bed. A father might become uncomfortable with his daughter's personal care when she starts to develop and menstruate. Residential care can give both parents and adolescents privacy and independence.

Support from Other Families

Families of children with disabilities often feel alone in the community because it is hard to find others with similar experiences. Meeting other families is a benefit of residential care. They can find the comfort of real understanding through support groups and other activities, sometimes for the first time.

Benefits for Children

Social Development

Finding acceptance and understanding among peers is a benefit of residential care. Where being disabled is the norm, children are not stared at or looked down on for being different. This helps them develop social skills and confidence. Unlike public schools, where children with severe disabilities can have difficulty participating in extracurricular activities, residential facilities may offer adapted sports and other recreational programs.

"When he was at home, our son's world was us and the television. He had no peers or social group. Now, at the school, he's one of the gang."

Development of Maturity

Because they can do more for themselves in an accessible environment, are away from their parents, and have to get along with a wide range of people, children in residential care may be challenged to mature faster than children living at home. Residential programs that provide specialized training in independent living skills, self-care, financial management, and job skills help prepare adolescents for adulthood. Goals for children with disabilities vary widely depending on their cognitive abilities, emotional maturity, and physical needs. A benefit of residential care is that learning and training need not stop in the classroom. A comprehensive residential program will try to help the child apply classroom lessons and therapy skills to daily life in a 24-hour environment. Public schools usually do not have the expertise, nor parents the time, to provide such intensive help.

Reliable, Centralized Care

Children in residential facilities also benefit from reliable and consistent care. Many programs have on-site medical and dental care as well as physical, occupational, and speech therapy services. On-site care greatly reduces transportation for special services and gives children more time for education, therapy, and play. It also reduces the risks of medical complications or injuries during transportation, particularly in situations where drivers and attendants are not well trained or supervised.

Disadvantages of Residential Care for Families

Loss of Control

When parents talk about the stresses of residential care, they most frequently mention how difficult it is to lose control over their child's care. They worry that no hired staff will be as devoted to their child as they are or care for their child as well as they do. The special tricks, preferences, and methods that parents learn as they care for their child may become lost in the routine and schedules of residential care. This can be upsetting for parents to observe, especially when a child cannot communicate wishes and preferences.

"When my son moved into a group home, he was terrified of being bathed because the staff did it so differently than I did at home. He couldn't talk, and they didn't know how much of what they said he understood. I used to go over and explain how I did things and what he was used to, but I could see that they didn't have the time or the patience. After a while, it got so bad that I didn't want to visit him, because I was afraid of what I would see. At the same time, I was afraid that he would suffer if I didn't go, because there would be nobody to speak up for him and see that changes were made."

Usually, as time passes and their child adjusts to being away from home and settles into new routines for care, parents begin to trust staff more and relax. But their anxieties are renewed if a particularly liked and trusted staff person leaves the facility or

if a mishap occurs with their child. One adolescent at a residential school wandered off unsupervised on a nature trail, got his wheelchair stuck in a rut, and had to be rescued. His parents were upset, but then relieved when the school grounded him for a week, just as they would have done. Parents also feel more worried and helpless when their children are ill or recovering from surgery and tend to call or visit more often at these times.

Parents handle their frustration and anxiety about loss of control in different ways. Some deal with disagreements as they occur, while others stockpile complaints until they explode. At times a matter that may seem unimportant to others is the spark that ignites feelings. For instance, parents often complain about their children's clothes getting lost.

Loss of Contact

While control issues usually subside over time, the pain of separation may not. Parents miss their children when they live away from home. They do not have the day-to-day contact of being together and sharing the little things as well as big events. The loss is greater when distance makes visiting difficult or funding sources limit the number of hours or days a child can spend away from the program to visit family.

The Empty Nest

Parents often go through the empty-nest phase when a child moves to residential care. If family life has revolved around caring for a child with severe disabilities, parents can get depressed when the focus shifts. They may have difficulty finding new interests and new ways of being a parent without being the primary caregiver.

This is likely to cause stress in a marriage when communication between partners has focused primarily on the logistics of care. Once the child moves to a residential facility, spouses are left alone with each other and can no longer avoid the conflicts and distance between them, and many eventually divorce.

Guilt

Still another stress on parents is guilt, particularly if they feel that choosing residential care means they have failed as parents or are being selfish. Doubt and guilt are especially common in families where children cannot express their wishes.

"We felt we had to put David in a nursing home for the good of everyone else in the family. But I'm sure if he could talk, he'd say he would rather be home with us."

Parents' guilt is deepened when other people criticize them for ***"abandoning"*** their children. Professionals may contribute to this. One father recalled the feeling of being put on trial by social workers, who asked why he couldn't take care of his quadriplegic son at home. ***"I'd always have to explain to them that I couldn't do it,"*** he said. ***"I had to work."*** Sometimes the criticism comes from relatives, friends, or acquaintances. Parents feel particularly hurt when they perceive that many are quick to criticize them, while few are willing to help. ***"People would ask me how I could do this to my child,"*** one parent recalled. ***"That made me really angry and want to scream at them, 'Why don't you try living with us for a week?'"***

Disadvantages for the Children

Homesickness

Just as their families miss them, children can be lonely for parents, siblings, relatives, and familiar surroundings. One boy in a nursing home looked forward with such longing to his father's weekend visits that, for many years, the father never dared skip a Saturday or Sunday.

Relying on Others for Care

Children may feel anxious about being handled and cared for by a large and changing staff. In addition to new routines and methods of care, they may have to struggle with new expectations and responsibilities. This can be hard for children who were used to relying on parents to meet all their needs.

Getting Along with Peers

Children also must get used to living with groups of peers. They are likely to have less privacy than at home, and they have to learn how to share attention from staff and share resources. Other residents may not always welcome newcomers, making them feel even more rejected and homesick in the beginning. One child remembered, ***"At first I felt disliked and ganged up on. It took me a while to get in with the crowd."***

Need for Compromise

No facility can completely satisfy the wants of any child or family. Compromises must often be made. Staff can be short-handed and overworked. Children may not get as much attention as they were used to at home. Some staff members are likely to be more friendly and conscientious than others. Just as lost clothing seems a symbolic issue for parents, institutional cooking is something children often complain about. They miss home cooking and the love and nurturing it signifies, which no facility can replace.

"Sometimes he pleads with us to take him home again. And it's really hard for me when I have to tell him no. I always remind him of how much we all love him, but I know how much he misses us."

Summary

Residential care will never be the same as home. Some children adapt to living away from home more easily than others. Some families find adjusting to the absence of their child more difficult. For all children and families, adjusting to residential care is a process that involves weighing the advantages as well as the drawbacks.

Much of the comfort or anxiety that families feel after a child enters a residential program is related to the child's adjustment and the quality of care that is given. Families must choose carefully when they consider a residential program. It is much less stressful for both child and family to make the best choice the first time, rather than to relocate the child more than once. The next chapter gives suggestions and guidelines on what to look for.

Chapter 6

Choosing a Residential Program

"What do I look for in a program? What questions should I ask?" Experienced parents suggest starting to explore options several years before the need for residential care arises. Finding a program that can meet a child's medical, therapeutic, and educational needs and then getting the required funding are complicated processes. Learning what is available, visiting programs, and talking with staff can help families decide whether residential care is a possibility they should consider.

One advantage to starting early is that families are then more prepared if circumstances change. For instance, family members who help with care of the disabled child may move away. Community based services may be cut back or payment restricted. Teachers and resources in local schools change. Above all, the needs of the child may change over time and lead families to reevaluate their situation.

Limits on Choices

Many parents' choices for residential care are limited by factors beyond their control. Three factors that most often narrow the choices are funding, location, and level of care.

Funding differs from state to state. The only commonality is the lengthy and difficult process to obtain it. States have varying formulas for funding residential programs with public monies. These may include appropriations for special education, Medicaid, developmental disabilities, and public health.

One cause of frustration for parents is the difficulty of matching resources with the needs of their child. The child's medical, physical, behavioral, and cognitive needs may be major factors in establishing funding eligibility for specific residential programs. A child's cognitive level can be too high or too low; behaviors can be considered too aggressive or require too much supervision. Care that requires skilled nursing may be compared to physical care that is considered ***"maintenance."*** All these distinctions can affect funding and choices for residential care.

Once funding has been approved, many parents still have to go through the hurdle of waiting for an opening. When residential programs are full to capacity, there may be a wait of weeks or months until a vacancy is available. This waiting period can be stressful because it prolongs the emotions of separation.

Some families first use residential programs for respite or temporary relief from daily care. When this short-term experience is positive for the child and family, the long-term decision is sometimes made more easily. Similarly, some residential programs have day school programs. The move to residential care may be eased by familiarity with the school, other students, and some of the caregivers.

Location

Distance from home affects how often family, relatives, and friends can visit a child. If the program is nearby, families can much more easily see their child, check on adjustment to the program, speak with staff, and see firsthand what is going on. However, the benefit of being close must be weighed against what else the program has to offer. A program may offer the advantage of being near family but not have the therapeutic or educational opportunities that are available in a program that's farther away from home.

Being close does not necessarily insure communication either. One parent reported, ***"We had better communication with the staff when our daughter was in a program 90 miles away than when she was in the public school in our neighborhood."***

Whether a program is in an urban, rural or suburban area is another consideration. Each offers advantages and may be more or less familiar for the child and family.

Gathering Information

The rest of this chapter is divided into two sections. First, there are questions families need to ask about the program. Second, there are questions that families need to ask themselves.

Questions for Programs

The most important elements to evaluate are:

- √ Location and condition of the facility
- √ Staffing and qualifications
- √ Social environment
- √ Involvement of parents
- √ Educational programs

Conditions in the Facility

Checking out the physical conditions of a residential program may be one of the easier things for families to do:
Suggested areas to consider:

- √ What is the general state of cleanliness and neatness?
- √ What is the general impression of maintenance and building repair?
- √ How close together or spread out are buildings and grounds?
- √ Are grounds and buildings accessible for wheelchair users and other children with mobility impairments?
- √ What type of decor is there?
- √ How crowded or roomy are living conditions for residents?
- √ What type of fire protection and emergency exits are available?

Staff Qualifications

The person who is ultimately responsible for the child's medical care is the physician. It is important to know how the residential program provides medical services, the qualifications of the medical staff, and how often they are on-site or available by consultation.

Suggested questions to ask:

- √ Can your child's current physician or specialists remain involved?
- √ If not, how will records be transferred and consultations arranged?
- √ If your child needs to be hospitalized, how is the hospital chosen and what voice do you have in this decision?
- √ What are the procedures for medical emergencies? How and when will you be informed?

It is important for families to know about the experience and training of primary care staff. This includes nurses, nursing assistants, physical, occupational, and speech therapists, and any other staff involved in a child's care. While the child's physical care falls under the responsibility of the director of nursing, the nurses and aides are the ones who provide the care every day and have the most contact with a child. Therefore, parents suggest talking with a variety of staff and asking how nursing coverage is assigned.

Suggested questions to ask:

- √ How many of the staff are experienced in the special needs that your child has?
- √ What kind of training will the facility provide for staff who are not experienced with your child's needs?
- √ What kind of communication systems are set up for staff to advise you about your child's condition, needs, and progress?

- √ What kind of licensing or accreditation does the program have and what does that mean?
- √ How many staff will care for your child?
- √ Will your child have an assigned nurse and care team, and, if so, how frequently will this change?
- √ How does coverage vary by shift or time of day?

Psychosocial Environment

Physical care and medical attention are only part of what a child needs. Families stress the importance of visiting programs to ***"see how they feel."*** Parents suggest dropping in for an informal and unscheduled visit. Notice how staff interact with children and notice how staff interact with each other.

Suggested questions to ask:

- √ Does the facility feel more like a hospital, a school, or a home?
- √ How much privacy do children have in their living areas?
- √ How are rooms arranged and decorated?
- √ How are roommates selected?
- √ How are peer groups chosen? Are they housed together according to chronological age, by developmental needs, or by functional abilities and limitations?
- √ What kinds of opportunities are available for playing games and sports and participating in other structured and informal activities?
- √ What social activities are available within the program?
- √ How often do children go on outings in the community?
- √ How do children interact with each other?
- √ What is the balance between individual and group activities?

Discipline is an important part of raising a child. Traditionally, discipline is the responsibility of parents, but when a child lives in a residential program, it shifts to the staff.

Suggested questions to ask:

- √ What is the program's philosophy about discipline?
- √ Does the program have a clear, written policy on client or resident rights?
- √ How do staff respond to and handle problems with behavior, temper tantrums, withdrawal, or rule breaking?
- √ How much input do parents have in designing rules for discipline, such as deciding whether discipline is verbal or physical?
- √ How are progress and obeying the rules rewarded?
- √ What type of training is given to the staff on child development and specifically on handling and responding to behaviors?
- √ Is the staff interested in learning about the family's expectations for the child's behavior, what responsibilities the child had, and how discipline was given at home?
- √ How similar is the family's philosophy about child rearing and discipline to that of the residential program?

A fear of many parents is that their child will be abused, either sexually, physically, or emotionally, when living away from home.

Suggested questions to ask:

- √ How does the program insure that abuse will not occur?
- √ How will it respond if there is any reason for concern or cause to investigate?
- √ When will the family be informed and how will they be involved in the investigation?
- √ If there has been abuse, how will the facility insure that the child is protected and treated and that abuse does not happen again?

Involvement of Parents

When a child moves to a residential program, many parents fear that they will have to ***"give up"*** their child. Although the physical responsibility for care may shift to professional caregivers in a residential program, parents still remain *the parents*. They still retain the emotional commitment to raise their child, look out for their child's best interests, protect their child from harm, and insure that their child has the opportunities to reach her or his potential. One parent considers a residential program similar to a boarding school for her child. ***"I see it as a special place, offering special services to special children with special needs."***

A residential program's philosophy about parental involvement will be reflected by visiting policies, opportunities for communication with parents, frequency of formal meetings and informal telephone communication, and opportunities for input in decision making.

Suggested questions to ask:

- √ How well do staff listen to the concerns of parents, ask for input from parents, and respond to insights from parents?
- √ How will parents communicate with physicians, nurses, social workers, and case managers?
- √ How often can parents take their child out of the program, either for day or overnight outings? If there are limits, are they based on insurance regulations or the philosophy of the program about parenting and visiting?
- √ What are the procedures for handling complaints from parents?
- √ How easily can parents remove a child from the program if dissatisfied?
- √ Does the facility have a parent advisory committee?

Child's Educational Needs

For many families, the decision to seek residential care also reflects concerns about their child's education. Although the federal and state ***"special education"*** laws protect the right of a child with a disability to a ***"free and appropriate"*** education in the ***"least restrictive environment,"*** local schools may find it difficult to meet a child's needs.

When considering a residential program with educational services, it is important for parents to become involved right in the beginning and to stay involved.

Suggested questions to ask:

- √ What do you see for my child's future?
- √ How can you help prepare my child for the future?
- √ What is your philosophy about educating students with severe disabilities?
- √ How can your teachers help meet my child's special needs?
- √ How will you decide what kind of program my child needs?
- √ What kind of physical help can you give my child in the classroom?
- √ What kinds of technological aids, including computers, are available?
- √ What results do you expect from your class?
  - What do you expect from all your students?
  - How do you determine individual expectations for each student?
- √ How will you measure and evaluate the progress of my child?
  - Are classes graded or ungraded?
- √ What type of vocational training and academic options are available?
- √ How will education prepare my child for life as an adult?

Questions for Families

When exploring the choices for residential care, parents need to ask themselves some critical questions.

Suggested questions to ask:

- √ Why am I thinking about residential care? And why now?
- √ How severe are the physical, emotional, and financial stresses of providing home care?
- √ What effect are these stresses having on me, my child who is disabled, my spouse, and my other children?
- √ How will these stresses change in the future?
- √ Will my child have more social, educational, and recreational opportunities in a residential program?
- √ What does my child want?
- √ What do I want for myself and my family?
- √ How would residential care affect the siblings of my disabled child?

Summary

As one parent said, ***"Basically, you have to ask yourself, 'How much can I do to help my child, and can I do it forever?'"***

Conclusion

Residential placement is an option that can benefit families and their children with severe disabilities in many ways. For parents, it can offer relief from the burdens of home care, security regarding the future needs of their children, an opportunity to separate and live their own lives, and a way of meeting and getting support from other parents in similar situations. For siblings, it can free parents to give them more attention. For the children who are disabled, it can provide reliable daily care, centralized medical and dental care, an accepting community of peers, adapted social and recreational programs, specialized training for adulthood, and the chance to achieve normal separation from their parents.

On the other hand, residential care can have disadvantages. Parents lose some control over their child's care and rearing, feel anxious about their well-being in the facility, miss them, feel guilty for placing them, and go through identity struggles when they lose their role as care givers. The children are apt to feel that they are not getting the same amount of help and individual attention as they did at home. They may also feel homesick, anxious about relying on paid staff, separated from siblings, and sensitive to rejection by other children in the residence.

The choice of home care also carries benefits and disadvantages. Among the benefits for parents is an increased sense of mastery and control of their child's care. Families feel more unified because they are together. Time and energy do not have to be spent traveling to a residential facility to visit the child. The benefit to a child raised at home can be better physical and emotional health.

The chief disadvantage of home care for parents is the physical and emotional stress of constant responsibility. This restricts activities outside the home. Avoidance by relatives and friends can isolate the family even further. When parents are able to hire professional home care workers, they are relieved of some responsibility, but they lose privacy. Also, the financial costs of home care can be high. For the child with a disability, the disadvantage of home care can be lack of peers, difficulty getting specialized educational services, trouble finding adapted recre-

ational programs, and over-dependence on the family for physical care and emotional support.

Parents who have chosen residential care need reassurance that their children still are part of their families. Parents often feel an ongoing sadness that their children have limitations and differences and that these have made residential care a necessity. Often, too, they remain perpetually torn by feelings of guilt and obligation toward their children. They struggle for a balance between being involved and standing back and letting the program do its job.

Ultimately, families have to follow their instincts and do what is best for them, without letting anyone else be the judge. No two families are exactly alike. While home care might work for one, it might not for another. Also, all families change over time. There are typical points when home care becomes more stressful, such as when the child with a disability reaches adolescence, when younger siblings are born, and when parents become middle-aged. At such points, residential care is likely to be considered or reconsidered.

Parents think very carefully about their decision to move their child to a residential program and, once they have made it, they seldom change their minds and take the child back home. But they certainly have the option, and knowing that can be a comfort. They still retain all parental rights, although some choose to be less involved than others in the day-to-day details of their children's care. As one parent said, ***"I'll always be Phillip's mother, but I can't let him consume my life wholly. I have to find a happy medium."***

We hope this guide helps other families of children with disabilities find the balance that is right for them.

We also would appreciate your input and any suggestions regarding the improvement of this book and other topics of interest. Comments can be sent to Crotched Mountain Foundation, Attn: Marilyn Lash.

Resources for Families

Association for Care of Children's Health (ACCH)
7910 Woodmont Ave., S-300, Bethesda MD 20814
301-654-6549 fax 301-986-4553

ACCH is a leader in defining, promoting, implementing, and supporting standards for best practice and policy in the care of children and families. It has excellent reading materials for children and families on hospital care and annual conferences for parents and professionals.

Association for Retarded Citizens (ARC) of Georgia
Parent Empowerment Project
2860 East Point St., S-200, East Point GA 30344
404-761-3150 fax 404-767-2258

This organization is for parents and individuals or groups concerned with the quality of life of persons who have mental retardation, developmental disabilities, or other disabilities.

Brain Injury Association (BIA)
1776 Massachusetts Ave., S-100, Washington DC 20036
202-296-6443 fax 202-296-8850

Provides information and resources for persons with brain injury and their families. Has a national network of 44 state chapters with support groups. Hosts national conferences on brain injury. Provides information on resources and has written materials on brain injury and prevention.

Disability Rights Education and Defense Fund, Inc. (DREDF)
2212 6th St., Berkeley CA 94710
510-644-2555 fax 510-841-8645

This is a national law and policy center dedicated to furthering the civil rights of people with disabilities and to promote their integration into the mainstream of society.

Exceptional Parent
209 Harvard St., #303, Brookline, MA 02146
800-534-1910 (for orders)

Magazine written especially for parents of children and young adults with disabilities and special health care needs, as well as the professionals who work with them. Comprehensive publications catalog includes books for parents on many types of illness and disabilities. Publishes annual resource catalog.

Family Resource Coalition
200 South Michigan Ave., 16th floor, Chicago IL 60604-2404
312-341-0900 fax 312-341-9361

Provides programs that work directly with families to bolster parents' ability to help themselves, promote healthy childhood development, and prevent child abuse and neglect, teen pregnancy and juvenile delinquency.

Federation for Children with Special Needs
95 Berkeley St., S-104, Boston MA 02116
617-482-2915 fax 617-695-2939

Child advocacy and information center consisting of staff members who are parents of children with special needs. Information that is available includes special education laws, health issues, resources, coordinating care, and obtaining services. Coordinates national network of Parent Information Centers.

National Association of Developmental Disabilities Councils (NADDC)
1234 Massachusetts Ave., NW, S-103, Washington DC 20005
202-347-1234 fax 202-347-4023

Overseeing agency for state councils that plan, advocate, and work for change on behalf of people with developmental disabilities and their families.

National Center for Youth with Disabilities (NCYD)
University of Minnesota UMHC Box 721
420 Delaware SE, Minneapolis MN 55455-0329
800-333-6293 TDD 612-624-3939 fax 612-626-2134

The Center provides easy access to current research findings and information on resources and advocacy efforts, and disseminates policy and program development information to agencies, health and human service professionals, educators, policy makers, parents, and youth.

National Center for Children and Youth with Disabilities
P O Box 1492, Washington DC 20013-1492
800-695-0285 fax 202-884-8441

An information and referral center that provides information on disabilities and related topics. A special focus is children and youth with disabilities, birth to age 22. Produces publications on disability and educational issues (many in Spanish). Also available on the Internet (gopher@aed.org).

National Easter Seal Society
230 West Monroe St., S-1800, Chicago IL 60606-4802
800-221-6827 fax 312-726-1494

Organized to help people with disabilities achieve independence. Easter Seals provides quality rehabilitation services, technological assistance, and disability prevention, advocacy, and public education programs. States have local chapters.

National Information System and Clearinghouse
Center for Developmental Disabilities Education
USC School of Medicine, Columbia SC 29208
800-922-9234 fax 803-935-5250

Specialists assist families in accessing services such as parent support/training, advocacy, health care, financial resources, assistive technology, early intervention, child protection from abuse and neglect, and other information resources.

National Parent Network on Disabilities (NPND)
1727 King St., S-305, Alexandria VA 22314
703-684-6763 fax 703-836-1232

The Network provides a forum and national voice for parents of children, youth, and adults with special needs. NPND shares information and resources in order to promote and support

the power of parents to influence and affect policy issues concerning the needs of people with disabilities and their families.

National Association of Protection and Advocacy Systems (NAPAS)
900 2nd St., NE S-211, Washington DC 20002
202-408-9514 fax 202-408-9520

NAPAS is a federally mandated system in each state and territory that provides protection of the rights of persons with disabilities through legally based advocacy.

National Spinal Cord Injury Association (NSCIA)
8300 Colesville Rd., Suite 551, Silver Spring MD 20910
301-588-6959 or 800-962-9629 fax 301-588-9414

In Touch with Kids is a special program of NSCIA that offers a support network for children with spinal cord injury or illness and their families. It provides opportunities for sharing ideas, feelings, resources, and innovative problem-solving with other families.

PACER Center
4826 Chicago Ave., South Minneapolis MN 55417-1098
612-827-2966 fax 612-827-3065

A statewide nonprofit organization that serves families of children and adults with disabilities. PACER programs help parents become informed and effective representatives for their children in early childhood, school-age, and vocational settings. Through knowledge about laws, resources, and parents' rights and responsibilities, families are better equipped to work with agencies to obtain appropriate services for their sons and daughters.

Project School Care/Children's Hospital
Judge Baker 2, 300 Longwood Ave., Boston MA 02115
617-355-6714 fax 617-355-7940

Project School Care documents and fosters access to educational services by children who depend on tracheostomies, gastrostomies, intravenous shunts, peritoneal dialysis, ileo/colostomies, ureterostomies, and other daily nursing procedures.

Sick Kids (Need) Involved People of NY Inc. (SKIP)
13th floor, 545 Madison Ave., New York NY 10022
212-421-9160 fax 212-759-5736

SKIP specializes in case management for people at home with complex medical needs and developmental disabilities. It makes families equal partners in their children's case management and service decisions.

Washington Parents Are Vital in Education (PAVE)
12208 Pacific Hwy. SW, Tacoma WA 98499
206-588-1741 fax 206-984-7520

The majority of Washington PAVE staff are parents who have children with special needs. It provides information and resources to people whose lives are linked to children and adults with disabilities.

US Department of Justice/Civil Rights Division
PO Box 66738, Washington DC 20035-6738
800-514-0301; TDD 800-514-0383 fax 202-307-1198

The Department of Justice enforces the Americans with Disabilities Act (ADA), a comprehensive civil rights law for people with disabilities. It enforces the ADA's requirements for employment practices, programs and services, and public accommodations.

ORDER FORM

This book is provided free of charge to families. Shipping charges apply to all copies ordered.

Families: _____ copies @ NO CHARGE

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I am a professional who will give families:

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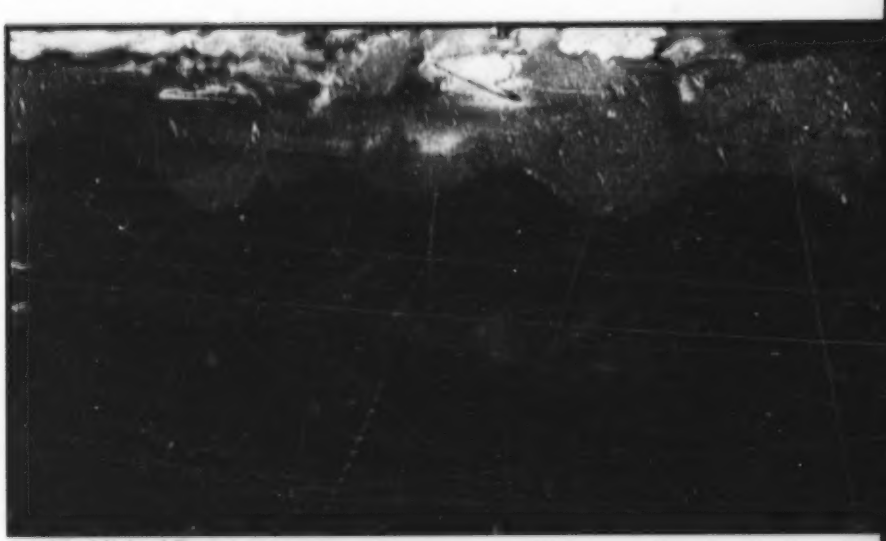

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